Patient Facility Representative (PFR) Alliance Meeting

May 4, 2023
Patient and Family Engagement
Program Team

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Today’s Agenda

- Meeting Reminders
- PFR Check-In
- Learn about the PFR Alliance
- QAPI
- New Resources
- Closing Remarks
Meeting Reminders

● All phone lines are muted upon entry to eliminate background noise/distractions

● We will be monitoring Chat throughout the meeting for questions or comments

● All slides will be shared within a week of completion of the meeting
Welcome to Our May Meeting!

Shezenna Andiappen, MSW
Patient Services Coordinator
The IPRO End-Stage Renal Disease Network Program includes four ESRD Networks:

○ Network 1: ESRD Network of New England
○ Network 2: ESRD Network of New York
○ Network 6: ESRD Network of the South Atlantic
○ Network 9: ESRD Network of the Ohio River Valley

The mission of the IPRO End-Stage Renal Disease Network Program is to promote healthcare for all ESRD patients that is safe, efficient, effective, patient-centered, timely, and equitable.
Network Check-In

- Which Network are you from?
  - Network 1 (Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont)
  - Network 2 (New York)
  - Network 6 (North Carolina, South Carolina, Georgia)
  - Network 9 (Indiana, Kentucky, Ohio)
Let’s Talk: PFR Alliance

Danielle Andrews,
MPH, MSW, GCPH
Health Equities Specialist
Network Check-In

- Is this your first meeting with the PFR Alliance?
  - Yes
  - No
  - Unsure

We want to hear from you!
Network Check-In

● Does your facility have other PFRs or Patient Advocates?
  ○ Yes
  ○ No
  ○ Unsure

We want to hear from you!
What is Patient Facility Representative (PFR) Alliance?

The Patient Facility Representative (PFR) Alliance is a patient advocacy group that provides patients, transplant recipients, and care partners the opportunity to share thoughts and experiences on ESRD care as well as develop different strategies on how to get more ESRD patients to become active within their care. The PFR Alliance also seeks to promote positive relationships between patients, provider staff, ESRD stakeholders, and the Network.

- The PFR Alliance supports the promotion of patient, family, and care partner engagement in ESRD care at the local community level, as well as promoting positive self-care management and relationships between patients, provider staff, renal community stakeholders, and the ESRD Network.
PFR Alliance Group Membership

As an active PFR Member you are expected to:

● Participate in monthly phone calls with the Network to provide feedback on patient’s needs, facility issues and educational resources.

● Coordinate social and educational events to increase awareness of ESRD
  ○ Lobby Days
  ○ Annual ESRD Luncheon
  ○ American Association of Kidney Patients (AAKP)/ NKF Patient Panels

● Participate in Network Quality Improvement project with your Facility Social Worker

● Participate in national quality improvement projects
  ○ ESRD National Coordinating Center Patient and Family Engagement Learning and Action (ESRD NCC NPFE-LAN) Calls
  ○ NCC Affinity Groups

● Become a Peer Mentor
Patient Facility Representative (PFR) Alliance Levels of Engagement

PFR Members

Are Introductory PFRs, these individuals that are looking to educate themselves on kidney disease and learn different ways to become a healthier patient living with ESRD.

QIA Champion

Are PFR leads, these individuals have demonstrated leadership ability at their dialysis facility and are looking to develop their advocacy skills.

- They speak with their ESRD peers and share their advice and experiences and act as a link between the ESRD community and the Network
- Participate in facility activities associated with QIA project

PFR-Patient Subject Matter Experts (PSME)

Are long-term dialysis or transplant patients that have been selected by the Network because of their dedication to patient advocacy.

- They conduct and participate in national, regional, and community programs focusing on CKD and ESRD
- Engage in resource development and are peer mentors
The Role of a PFR Member

● PFR Members are introductory members and are beginning to take on an active role as a member of their healthcare team by:
  ○ Working in collaboration with your medical team (nutritionist, nephrologist, social worker, etc) to determine your plan of care
  ○ Engage in early levels of Patient Advocacy within their facility

● PFR Members use their knowledge to educate their ESRD Peers by:
  ○ Reviewing and providing feedback on patient resources
  ○ Distributing resources to ESRD peers and Social Workers

● PFR Members attend Network-hosted webinars, meetings, lobby days, and informational sessions

● PFR Members will receive newsletters and text messages from the Network about newly created educational materials.

● Engage with the Network and other PFRs through our Facebook PFR Alliance Group
The Role of QIA Champions

- These individuals are patients that have taken on a leadership role within their dialysis facility.
- Participate with the Network at the local facility-level, as a patient representative in Quality Improvement Projects:
  - Patient Family Engagement (PFE)
    - Peer Mentoring, Quality Assurance Performance Improvement (QAPI), and Life Planning
  - Behavioral Health (Depression)
  - Vaccinations
  - Hospitalizations
  - Home Dialysis
  - Transplant
- Attend monthly PFR meetings and participate in presentations from their QIA leads to further understand their role in the ongoing project.
- Assist facilities in creating activities and interventions that educate and help patients cope and adjust to changes made to improve dialysis treatment.
- Develop educational bulletin boards, host lobby days, community fairs, and distribute resources to patients and staff at the facility and in your community.
- Gathering patient feedback in the facility on Network Interventions.
The Role of the PFR: Patient Subject Matter Experts (PSMEs)

- Provide input to the Network into the development of informational or educational materials for patients and families and caregivers
- Participate in the Network’s quality improvement projects
- Engagement in the Network quality improvement project to ensure the highest level of care
  - Offers a patient perspective during Network QIAs presentations and huddles
  - Offers a patient perspective to the Network during the development of interventions and resources
  - Provides patient education and work with their facilities in the QAPI meetings to promote best practice strategies
  - Assists in Network educational resource creation
  - Becomes an ambassador for your QIA project
    - Actively engage with your ESRD peers and promote and dispense your QIA project materials and resources
PSME-ESRD NCC NPFE LAN/ Affinity Groups

Each year, the NPFE-LAN holds four separate groups, called Affinity Groups, focused on specific areas of dialysis and transplant care. The groups meet bi-monthly by webinar (phone and/or computer) to share experiences and discuss ways to improve the quality of care for kidney patients and meet the Centers for Medicare & Medicaid Services (CMS) quality improvement goals.

- Five PSMEs from each Network are nominated to work collaboratively with the NCC
- Attendance is mandatory with the exception of illness and home life stressors
- The Affinity Groups meet monthly to discuss:
  - Patient’s perspectives on the national issues pertaining to dialysis
  - Patient’s feedback on ESRD NCC Resources and videos
  - National discussions on the following topics:
    - Depression
    - COVID-19
    - Transplant
    - Hospitalization/Nursing Homes
    - Vaccinations
COR Call Participation

Each month, each Network meets with our Centers for Medicare and Medicaid Services (CMS) Contracting Officer’s Representative (COR) to provide updates on the Network’s collaborative efforts with the PSMEs and the PFR Alliance.

● If asked each participating PSME will provide:
  ○ Discuss the collaborative work being conducted between the PSMEs and The Network (Resource Development), as well as ongoing PFR Alliance activities
  ○ Discuss Affinity Group participation (if applicable)
  ○ Feedback on issues that are prominent within their Dialysis Facility and the ESRD Community
  ○ Discuss the additional work that PSMEs are working on outside of the Network
Patient Voice: Expert Thoughts

Connecting the Community

Every month the Network created a Newsletter that highlights upcoming events, Community Awareness (i.e. Sepsis Awareness Month, Suicide Awareness Month, Hispanic Heritage)

● We share new ESRD Resources (flyers, informationals, educational webinars)
● Provide access to ongoing to programs with Affiliated Programs (AAKP, DPC, Renal Support Network)
Questions?
Comments?
Engaging in QAPI as a Patient Facility Representative

Shezenna Andiappen, MSW
Patient Services Coordinator
Quality Assurance and Performance Improvement “QAPI”

QAPI is a combined approach that focuses on Quality Assurance (QA) and Performance Improvement (PI). QAPI uses patient and facility experiences as well as data to maintain and improve the safety and quality of care within dialysis and transplant facilities. While also incorporating caregivers and family members experiences in overall problem solving.
Quality Assurance and Performance Improvement “QAPI”

**QA-Quality Assurance:** focuses on the standards for quality of treatment and outcomes, as well as the organization’s process throughout the organization for assuring acceptable standards of care is maintained. **QA** is an ongoing process, the uses both present and past efforts to identify how an organization is performing, including where and why a facility’s performance is at risk or has failed to meet standards.
Quality Assurance and Performance Improvement “QAPI”

PI-Performance Improvement (also called Quality Improvement - QI) is the continuous study and improvement of processes with the intent to better services or outcomes, and prevent or decrease the likelihood of problems, by identifying areas of opportunity and testing new approaches to fix underlying causes of persistent/systemic problems or barriers to improvement. PI attempts to improve the processes involved in health care delivery and patient's quality of life.
Why you should participate in your facility’s QAPI Meeting

As a Patient Facility Representative your facility should be inviting you to their facility QAPI meetings:

● The QAPI meeting gives you the chance to talk to your dialysis facility staff about your concerns and other patient issues. Many times, the ideas and decisions that come out of QAPI meetings affect how the dialysis facility is run.
How to participate in your facility’s QAPI Meeting

- Once you’re invited to the QAPI meeting prepare the following:
  - Think about questions, concerns, or feedback you and/or other patients may have.
  - Be prepared to answer questions such as:
    - What do you think we are doing well in the dialysis facility?
    - What areas do you think we could improve in the dialysis facility?
    - What do you think are the most common reasons patients miss or shorten treatments?
    - What is the best way for staff to communicate with patients about their treatment?
PFR Involvement in QAPI

https://esrdncc.org/contentassets/2ef93a68b854467f916d9725011c0c06/helpptsunderstandqapi508.pdf
Because Your Voice Matters!

Your dialysis facility often invites patients like you to take part in what is called Quality Assessment & Performance Improvement (QAPI) meeting. You can also ask to take part in a QAPI meeting. This meeting gives you the chance to talk to the dialysis facility leaders about your concerns and other patient issues. Many times, the ideas and decisions that come out of QAPI meetings affect how the dialysis facility is run.

To have a good QAPI meeting experience, use this document to help you before, during, and after the meeting. Write down notes on what you would like to talk about with the healthcare team. This will help you stay on track during the meeting. Remember, your ideas can help make patient care better.

Before the QAPI Meeting

To prepare, think about questions, concerns, or feedback you and/or other patients may have. Ask the manager what topics will be discussed at the meeting. This might include:

- Facility improvement
- Preventing infections
- Fistula/Catheter education
- Reducing patient hospitalizations
- Home dialysis and kidney transplant education
- Emergency preparedness education

During the Meeting

In most cases, you will only be in the meeting for the first 15 minutes. You will be asked to offer suggestions for improving patient engagement and care. The dialysis facility leaders may ask you for your opinion and/or to share your experiences. The questions are meant to help the staff make the dialysis experience better for patients. If you do not understand something, just ask! You may be asked questions like:

- What do you think we are doing well in the dialysis facility?
- What areas do you think we could improve in the dialysis facility?
- What do you think are the most common reasons patients miss or shorten treatments?
- What is the best way for staff to communicate with patients about their treatment?

For more information, visit www.esrdncc.org/patients.

https://esrdncc.org/globalassets/patients/qapimeetingprep508.pdf
HIPAA or the Health Insurance Portability and Accountability Act was passed by Congress in 1996. It requires the protection and confidential handling of protected health information.

This resource addresses the following:

- Why is it important to allow posting of some patient information?
- How can a facility prevent HIPAA violations when posting information?
- What can a facility do to make sure HIPAA requirements are being met?

Let’s Patient Resources

Danielle Andrews,
MPH, MSW, GCPH
Health Equities Specialist
Patient Facility Alliance Manual

This brand new patient vetted resource includes the following:

- What is IPRO
- What is the IPRO ESRD Network Program
- What is the PFR Alliance?
- The PFR Structure (by tiers)
- Roles and Responsibilities
- How to stay active
- How to Join our Events
- Tips for Success
- PFR “Don’ts”
- How to become a Peer Mentor
- QAPI Meeting

Guidelines for PFRs and QAPI Meetings

This brand new patient resource includes guided instructions for all PFRs as they participate in their facility’s QAPI Meeting as well as task to take in the event that they cannot attend an upcoming meeting.

Next Steps
Network Check-In

- Are you interested in participating in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care?
  - Yes
  - No
  - Unsure
Patient Virtual Support Group

Join the Network in our virtual monthly patient support group!
- We want to understand your thoughts and experiences as an ESRD patient or caregiver
- Let us know what could have been done better, and what is working for you

Every 4th Wednesday of the month at 5:00pm ET
- Meeting Link: https://ipro.webex.com/ipro/j.php?MTID=m6de0a2dc11398746344a8dc525b9e7eb
- Call-In: 1-855-797-9485
- Access Code: 616 535 334
Next Steps

- **Follow** us on social media!
- **Join** the PFR Alliance Facebook Group [https://www.facebook.com/groups/ipropfralliance](https://www.facebook.com/groups/ipropfralliance)
- **Create** your IPRO Learn Account [https://esrd.iprolearn.org/login/index.php/](https://esrd.iprolearn.org/login/index.php/)
- **Save the Date**: February 2, 2022
- **Participate** in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care - volunteers needed each month!
- **Become** a Peer Mentor:
  - Understand the steps [https://esrd.ipro.org/patients-family/pfe/peer-mentoring/](https://esrd.ipro.org/patients-family/pfe/peer-mentoring/)
  - Register online: [https://redcap.ipro.org/surveys/?s=CJMXNF9DNR](https://redcap.ipro.org/surveys/?s=CJMXNF9DNR)
  - Have questions?
    - Contact Danielle Andrews at 516-209-5549
Follow Us on Social Media

- IPRO ESRD Network Program’s Facebook Page
- IPRO ESRD Patient Facility Representative (PFR) Alliance Group
- IPRO ESRD Network Program’s Twitter Page
- IPRO ESRD Network Program’s Linkedin Page
- IPRO ESRD Network Program’s Instagram
Questions?
Comments?
Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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